DOCUMENT RESUME

ED 368 089 EC 302 834

AUTHOR Rocco, Susan
TITLE New Visions for the Developmental Assessment of Infants and Young Children.
PUB DATE 4 Dec 93
NOTE 7p.; Paper presented at the Zero to Three Biennial National Training Institute (8th, Washington, DC, December 2-5, 1993).
PUB TYPE Speeches/Conference Papers (150) -- Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Clinical Diagnosis; *Developmental Disabilities; *Disability Identification; Early Childhood Education; Educational Diagnosis; *Labeling (of Persons); *Parent Attitudes; Parent Rights; *Student Evaluation

ABSTRACT

This paper describes the process of developmental assessment of infants and young children from a parent's perspective. The artificial and arbitrary nature of most assessments is bemoaned as failing to adequately recognize children's abilities that may be readily evident to parents in more natural settings. Assessments emphasizing children's failure to meet a certain developmental milestone on schedule are criticized as counterproductively negative and disempowering, as is the accumulation of diagnostic labels that often occurs as a result. Four cartoons illustrate the paper. (PB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Susan Rocco
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

ED 368 089

New Visions for the Developmental Assessment of Infants and Young Children
Saturday, December 4, 1993

Presentation by **Susan Rocco**:

Aloha! I'm Jason's mom. I'm thrilled to have the chance to be with you today, and I have to tell you that gazing out over the sea of your friendly faces, I now know the true meaning of stark terror! If I faint, I want you to remember that I'm usually a fun person...

My job is to talk about the assessment process from a parent's point of view--what it feels like, what we hear, and what would make it better from our perspective. I'm a battle scared veteran of twelve years, but, gosh, I can remember those assessment days in early intervention as if they were yesterday. After the first disappointing assessment when Jason was nine months old, I'd face each new evaluation with a mixture of hope and dread. Would Jason have caught up? Had we fixed him yet?

Despite the smiles and warmth of the early intervention staff, I'd be tense. The protocol was that I would be asked to sit directly behind his chair (so as not to distract him from the task at hand). As he graduated from one intervention program to another I was asked to watch from behind a two-way mirror. My preference, of course, was to be in the same room with Jason so that I could at least reassure him with my presence, maybe sneak in a little pat on the back.

In or out of the room I was always assigned the role of observer. I guess I was lucky, though. Some of my friends whose kids went to other programs were not allowed to even observe the assessment process. We parents decided that the team was afraid we'd learn the assessment protocol and cheat by teaching our child the specific skills required by the assessment. They were right, you know. I spent fruitless hours between evaluations trying to get Jason to stack four blocks or to point to the flashcard with the red wagon. It didn't dawn on me to tell the assessment team that there were no red wagons in our real life.

The timing for the assessments was fixed--they were scheduled for his normal therapy times with little flexibility, and it took nearly an act of God to reschedule. What little flexibility we did have faded by the time he was a preschooler. Assessment teams set a date and kept to as strict a schedule as possible. Never mind that he had a seizure the day before. So what if it was past his naptime. Since I was so tuned in to his moods and needs I remember mentally assigning "discount points" so that I could later rationalize his poor test scores to myself and my husband.

My biggest frustration was that Jason's therapists would not allow the use of motivators during the assessment process. As I'd sit behind him and watch him ignore command after command, I used to yearn for a box of Dynamints so that Jason could show them what he really knew. Just one measly Dynamint in exchange for his best work. But somehow that was never allowed.

Even my reassurances that Jason could perform some of these tasks at home--like being able to pluck a Dynamint out of a shag rug with a neat little pincer grasp-- or that he was a whiz at some skill that the assessment never covered--like humming the tune to 40 or 50 songs--never seemed to be incorporated into the assessment results. If they didn't witness a skill with their own eyes, then it was considered heresay evidence.

Sound like Old Paradigm? Absolutely! Have we made tremendous strides in the assessment process over the last decade. You bet! Do we have a ways to

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☐ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

EC 302834

BEST COPY AVAILABLE

go? You bet! My esteemed panel members, Drs. Greenspan and Hilliard are going to put all the pieces together and share our new vision for the developmental assessment of infants and young children later in this presentation.

But if you will indulge me for a minute, I'd like to get past the history taking, past the observations , past the collection of performance data and talk about how the results of the assessment are communicated to families. I'd like to focus on what parents hear in the assessment process, and how that message affects their short and long range goals for their children.

Certainly when Jason was evaluated, and all too often today, evaluation results tend to focus on deficits and ignore strengths. What is Jason not doing that he should be doing. Or conversely, what is Jason doing (behavior wise) that no "normal" kid his age would do. My friend Joyce Metzger still calls her son's evaluations Glen's "Can't Do Reports".

Often the deficit is portrayed as how far a child is behind in meeting a developmental milestone. The whole concept of developmental delay was confusing to me. I took it to mean that Jason was behind in many areas but had the potential to catch up and be normal. I began to place inordinate attention on helping him catch up. When the next evaluation showed him even further behind, I took that as an indictment against my parenting skills. I figured that if Jason was scoring the equivalent of D's and F's on his assessments, then I was clearly flunking early intervention, too! I mean after all, I was his main caregiver.

Sometimes the deficit is conveyed as a lack in ability--a lack of attention, a lack of speech, a lack of fine motor coordination. There is an ancient Yogic expression--"what you put attention on grows in your life." You can imagine that when we parents focus totally on what's wrong with our children, that's all we see.

Which brings me to the issue of labels. For most parents who have not had much exposure to disability before their child was diagnosed, their first reaction to a particular disability label is based on the negative stereotypes and imagery they have seen portrayed by the media. Sometimes it seems as if the label swallows the kid whole. I like this cartoon about Venus de Milo, because it points out how a person's beautiful qualities are diminished by labeling. (see cartoon 1).

Jason had acquired a number of labels by the time he started preschool--speech delay, epilepsy, cerebral palsy, pulmonary stenosis, Transposition of the Great Vessels, severe mental retardation. I was only marginally depressed by all these negative labels until we were sent for a psychiatric consult by our diagnostic team. It was a month later, upon reading a letter that the psychiatrist sent to the school that we got the most crushing label of all--Atypical Pervasive Developmental Disorder. It came without any explanation or practical information about what kind of support would be the most helpful. This cartoon says it better than I...(see cartoon 2)

With such an emphasis on deficits and diminished expectations for future success, we parents generally begin to look for a way to thwart these negative prognostications. At the very best, we want a miracle cure. At the least, we want you to fix our kid to the best of your ability. If our toddler isn't walking, then how about physical therapy five times a week. We begin a frantic search for programs, and treatments and experts. We're putty in the hands of the traditional treatment-focused, top-down approach to intervention. We believe implicitly that you professionals have all the answers and therefore all the power. We are powerless except in our ability to manipulate the system.

I was never more powerless than when Jason was at Columbia Presbyterian as an infant recuperating from heart surgery. We spent three months there, fighting off one death defying complication after another, watching other people provide all of Jason's care. I quickly assumed those little tasks that I could do to help out the nursing staff--scout out blue baby blankets, run for coffee, keep track of Jason's numbers for the next shift. As time crawled on, I became more assertive. I was the watchdog perched at Jason's cribside, asking questions, making sure that each new shift of nurses and medical students and residents were aware of his needs and priorities of the moment. I used to sneak a look at his chart when no one was looking and memorize his blood gases. But despite these small attempts to gain back some of the control over Jason's care, I knew who had the Real Power.

Thereafter, whenever a new label was placed on Jason, I'd get a resurgence of that feeling of powerlessness. It was as if suddenly we'd been transplanted to a foreign world where I knew none of the language or customs. We were dependent on professionals and special programs to lead us out of the Wilderness.

Often we parents never stop to think of the price we pay for this over emphasis on therapeutic interventions and specialized programming. We forget about our children's social-emotional needs since they are not a focus of the assessment. We overlook our children's fundamental need to belong in order to place them in segregated facilities with special treatments and low staffing ratios.

So how can you as professionals re-phrase your messages to families to present a more positive expectation? How can we all make the assessment process an important opportunity to find out what children **can** do and what they are ready to learn.?

Well, we can begin with an emphasis on strengths and abilities.

Then we can de-mystify and de-magnify labels. We can sit down with families and tell them exactly what a particular diagnosis means in practical terms without reinforcing into negative sterotypes or expectations. A recent study by the Beach Center found that parents of children with Down Syndrome gave high marks to physicians who "avoided making predictions that limited their baby's potential or future quality of life."

I applaud the American Academy of Mental Retardation for its recent re-classification of mental retardation that recognizes strengths and goes on to define a system of support for each individual. They have also done away with the traditional pecking order of retardation--no more SEVERE or PROFOUND labels. We all know how negatively weighted these subcategories are. Reflecting that awareness our new Assistant Secretary of Education, Judith Heumann and has issued a call to the field to gain comments on whether the word "severe" should be replaced with the word "significant" in reference to disabilities.

I look forward to a day when labels become irrelevant. (cartoon 3)

We need to help families see that the disability or the label is just one small piece of who the child is. We need to stress that these are ordinary children with somewhat extraordinary needs for support. It's up to us to plant these positive visions until the rest of mainstreamed society catches up. Until one mother's dream is realized that the birth of every child be celebrated.

Judy Walker, the director of Pilot Parent Partnerships in Arizona, says that it isn't always true that parents are devastated by the fact that their child has a disability or even by the label itself. Rather many are devastated by all the negative things that people say or by the condolences they offer. Believe me,

you can make a difference by emphasizing abilities and by acknowledging the family's expertise.

My friend and guru, Norman Kunc, said something about expertise that was very empowering to me. He said that expertise has a lot to do with experience. Often parents look to professional experts to diagnose a problem or to offer advice on behavior, and they fail to realize that they possess rich expertise of their own, because they are experts on the child. And the child is always bigger than his disability label or his behavior at one point in time. It is in the new vision of developmental assessments that parents and profesionals truly share their expertise.

Above all, we need to focus on the supports needed to live a quality life in the community. There's a great quote I read somewhere that says, "the emphasis in early intervention must not be on creating nearly normal children but on enabling children and their families to have normal life opportunities." It is time that all children share in the the embrace of relationships and experiences which lead to enhanced quality of life.

I'm beginning to see the potential of early intervention to reverse the negative, tragic, needs-fixing mindset that befalls parents when they find out their kid is different. If we could start right there convincing parents that different is O.K.--that we truly value diversity and not just tolerate it--then we could restore a sense of normalcy to families. If we could show parents that their child's disability is just one small part of who they are, then we could get away from this perception that quality of life is inversely related to degree of disability. We wouldn't have to take away their dreams for their children. Well, maybe we could help restructure them a little, but they would have fine dreams intact. (cartoon 4).

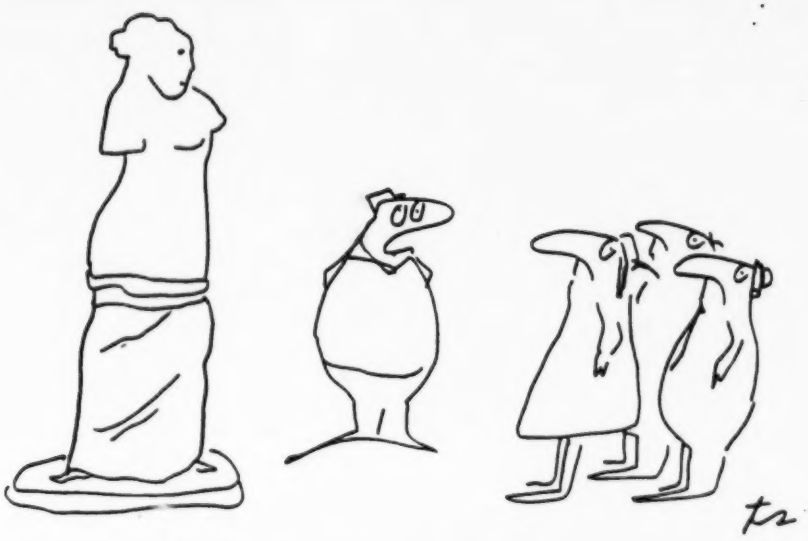
You know, my dreams for Jason have taken on a whole new flavor since he has been included with children his own age in regular education classes. I used to think the best we could hope for was a loving caretaker after I was gone and some extra frills to supplement his SSI checks. But you know, kids don't have the hang-ups we adults do when it comes to disability. They are able to see Jason's gifts and overlook his disabilities. Their dreams for Jason are that he have a normal life, that he has a job that he enjoys, that he has friends who accept him for who he is, that he gets rich! ... oh, and they want him to get a lowrider with hydraulics and learn to drive.

We need to listen to what these kids are saying. We need to also listen to what many people with disabilities are telling us--there is no pity or tragedy in disability.

What we're talking about here is planting the seeds of HOPE ..There is an old Chinese proverb that says: Hope is like a path in the country; there never was a road, but when many people walk on it, it comes into existence.

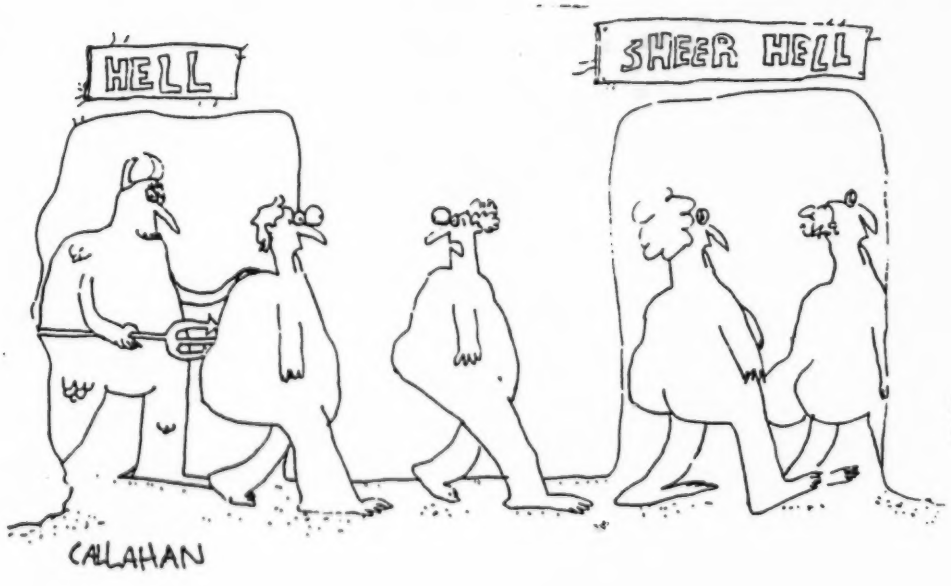
Thank you.

1



"She's the most priceless statue in the world. I dunno, somehow we just don't think of her as being handicapped."

2



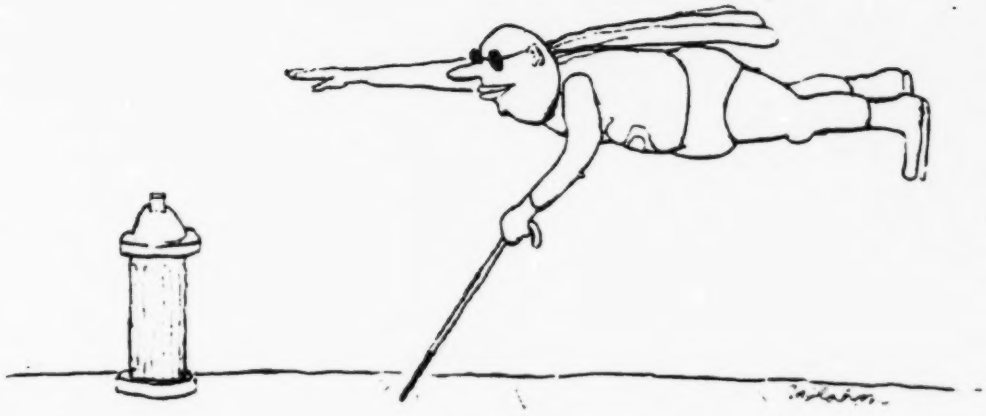
"Just when I thought things couldn't get any worse!"

BEST COPY AVAILABLE

3

"Yeah, I'm a rhinocerous, so what? Why do people always have to categorize each other?"

4



BEST COPY AVAILABLE